

EXECUTIVE SUMMARY

Throughout June and July 2004, *Marketing & Advertising Business Unlimited, Inc.* (doing business as Agency MABU) conducted a market research study to assess issues relating to children with special health care needs. Agency MABU researched the perceptions and opinions of two distinct groups:

- Families of children with special health care needs
- Pediatric providers.

A series of six (6) focus group sessions were held throughout the state with family members of children with special needs. Pediatric providers were surveyed using a combination of telephone interviews and direct mail surveys. A summary of key findings from each research study group is presented as follows:

Families of Children with Special Health Care Needs

Focus group findings:

General Feedback

Participants greatly appreciated the opportunity to share their thoughts and opinions regarding ways to improve the coordination of care for their children. However, several participants at each session voiced concerns that their feedback would not be taken seriously. They questioned whether or not any positive change would occur as a result of the research study and needs assessment.

Many participants expressed frustration regarding the difficulty with accessing information, services and support for themselves and their children. They talked about the difficulty associated with caring for a child with special needs. Many of the participants talked

about “burning out” both emotionally and physically due to the demands of caring for their child(ren), while at the same time having to “fight” for any services or support from State agencies and other related organizations.

The majority of the participants made favorable comments regarding the professionals who are directly involved with the care and coordination of services for families and children with special health needs. This list includes physicians, therapists, case workers and support staff.

Opinions varied from region to region regarding overall satisfaction with the coordination of care; however, there was a common theme that emerged. Many of the participants felt they are looked “down upon” by people who administer financial assistance programs. Comments were shared such as: “they treat us as if we’re trying to take advantage of the situation for our own financial gain,” “we have to fight for everything we get,” and “these employees should be our best advocates, not our worst adversaries.”

The highest level of concern and frustration was expressed by parents of children with chronic and/or multiple health care conditions, especially those children requiring specialized, ongoing care and attention by parents, pediatric providers and others. Parents of children with less complex or less comprehensive needs were far more likely to speak favorably of programs and services available to meet their child’s needs. The biggest gaps in service, support and funding appeared to be among families of children with severe, complex and chronic disabilities.

Accessing Information About Programs/Services

Participants gather and receive information about programs and services for themselves and their children from a wide variety of sources and mediums. Many participants access information directly from their case manager(s), physicians and other caregivers, and family support networks.

Families expressed a need for a centralized source for information. They are often confused as to where to get information. A great deal of their time and energy is spent researching information regarding services, financial assistance and other support. Concerns were also expressed regarding inconsistencies with the information received from various sources.

Working With Health Care Professionals

Many professionals are involved in working with families and their children. This list of professionals includes, but is not limited to: health care professionals, public health agencies, case managers, special education staff.

Participants expressed concerns about a lack of coordination among these various professional groups. Frustration is greatest in areas relating to the duplication of paperwork required by the various professionals.

On a positive note, the participants felt that health care professionals, in general, are sincerely concerned about the well being of children and their families.

Assuring Quality Care

According to the participants, the primary means currently in place to assure quality care for children with special health needs is oversight by their parents/families. Parents stated that they often know their children's changing needs better than any other professionals involved in the coordination of care. Thus, many parents expressed a desire to be more involved in the treatment process for their child(ren). They expressed concerns that health care professionals often overlook or under value the input and advice that parents can provide to improve the quality of care for their child(ren).

Other means of assuring quality care include: treatment plans, IEP in schools, respite care, specialty clinics, and family care networks.

Access To Needed Services

Many of the participants have sought services for their children from out-of-state providers and programs. The most frequently referenced locations included Minnesota and Colorado. Participants expressed serious concerns about the lack of medical coverage when seeking support outside of North Dakota. They are often forced to stay in North Dakota due to funding restrictions when they know that more specialized care is needed and available elsewhere. As a result, several participants mentioned that they seek care outside of the state and pay for services on their own. Those without the means to do so feel that their choices are limited, and they need to accept sub-standard care as a result.

As for services lacking in their community, the participants identified the following: 1) training for parents/families to deal with caring for children with special needs, qualified respite care professionals, pediatric specialty providers (especially in smaller communities), mental health care professionals, and OT and PT rehab professionals.

Family Involvement

Participants say that there exists a need for more respite care. Many families are overwhelmed with the responsibilities associated with caring for children with special health needs. They need support from qualified and well trained respite care providers. However, they are adamantly opposed to assuming the coordination of respite services for their children. They believe other organizations should provide this service on their behalf.

Families believe that they are the primary coordinators of care when it comes to their children. They believe that this should remain their role, and that others (especially doctors and therapists) should more actively involve them in the decision and treatment process. Too often, their input and opinions are not considered or valued.

Role of Children's Special Health Services (CSHS) Unit

The majority of participants were not aware of the existence of the Children's Special Health Services (CSHS) Unit.

When asked to identify the potential role for such a Unit, the participants offered the following ideas: centralized source for information, advocate for families and children, coordinator of care (much like an admissions counselor at a college), training for daycare providers to care for children with special health needs, and resource for questions about financial assistance.

Financial Matters

Numerous stories were shared regarding the stressed financial situations experienced by many of the families caring for children with special health needs. A great deal of frustration exists with the system associated with receiving financial assistance. Common concerns expressed by participants include: “too much paperwork,” “assistance continues to be cut,” “we have to fight for everything we get, and “it’s better to be poor and single. That’s the only way families can get the help they need.”

Very few of the participants stated that their child(ren) have been denied health services; however, many were denied coverage for seeking care outside of the state. Also, many stated that they don’t seek coverage for many services because the process is far too encumbered and degrading.

Other Feedback

The session attended by people of Native American descent expressed concerns that they are looked down upon by people who are supposed to be providing assistance. They don’t feel that their unique cultural needs and concerns are being addressed.

Participants expressed a desire to have more workers with minority status as employees of the State and other agencies.

Pediatric Providers

Direct mail and telephone survey findings:

Pediatric Providers

A cross section of pediatric providers from across the state participated in the telephone and direct mail surveys. A total of 40 telephone calls and 308 direct mail surveys were completed by pediatric providers including:

- Physicians (pediatricians, pediatric specialists, child & adolescent psychiatrists and family practice doctors)
- Occupational Therapists and Physical Therapists
- Speech/Language Therapists
- Insurance/Payers (Medical Directors, case managers at BCBSND, IHS and Medicaid)
- CSHCN Case Managers and Care Coordinators
- Mental Health Professionals
- Public Health Nurses and Administrators
- Special Education Professionals
- Durable medical equipment providers
- Directors of inpatient pediatric departments
- Home health nursing directors
- Audiologists
- Community Resource Coordinators (CRC's)

This group of professionals serve patients and clients throughout North Dakota in cities both large and small. Those who participated in the survey process are representative of the total population of pediatric providers across the state.

The majority of pediatric providers who completed the survey process have positions which require them to work with children with special health care needs and their families on a regular basis (46.8%). Furthermore, the majority of those who participated in the research study, have provided professional services in North Dakota to children with special health care needs for six (6) or more years (69.1%).

Availability of Resources

When asked to rate the availability of resources in their community to meet the needs of children with special health care needs, the largest majority responded “fair” (37%) or “good” (26.3%). A smaller percentage rated this category “poor” (10.4%), “very good” (17.9%) or “excellent (4.9%).

Barriers to Providing Services:

When asked to identify barriers to providing services to children with special health care needs and their families, pediatric providers identified four major areas of concern:

- #1 – Lack of awareness about available services
- #2 – Lack of adequate public and/or private health insurance coverage
- #3 – Lack of respite services or other family support services
- #4 – Lack of knowledge about accessing the health care system

Transportation and travel was also identified by numerous survey respondents in written comments to this question. Other frequently mentioned barriers in written comments included:

- Lack of child psychiatrists and other mental health professionals
- Costs not covered by Medicaid or insurance

Barriers Within the Delivery System:

When asked to identify barriers within the delivery system relative to children with special health care needs and their families, pediatric providers identified five major areas of concern:

- #1 – Lack of coordinated funding system
- #2 – Fragmentation of services
- #3 – Lack of information on community and state resources
- #4 – Lack of multi-disciplinary clinics
- #5 – Lack of family-centered approach to care

Other barriers identified by a number of survey respondents in written comments to this question include:

- Unmotivated parents or too busy to apply for services
- Lack of culturally-relevant services
- Lack of coordinated funding system

Service Needs Within Communities:

When asked to identify services that are lacking within their community to provide comprehensive care to children with special health care needs and their families, pediatric providers identified four major areas of concern:

- #1 – Respite care or other family support services
- #2 – Mental health services
- #3 – Community education about children with special health care needs
- #4 – Support and discussion groups for families

Other services which are lacking that were identified by survey respondents through written comments to this question include:

- Mental health services
- In-home services
- Specialty pediatric care
- Daycare

Role of Children's Special Health Services (CSHS) Unit:

When asked to identify the role that the CSHS unit should serve relative children with special health care needs and their families, pediatric providers identified five primary roles:

- #1 – Building awareness and linking families to available services
- #2 – Partnering/Coordination/Collaboration with other organizations
- #3 – Payment of care for eligible patients and families
- #4 – Case management
- #5 – Sponsoring multi-disciplinary clinics

General Recommendations

Based on the research findings from the focus group sessions, telephone interviews and direct mail surveys, the following recommendations are presented for consideration:

- Increase the availability of trained respite care providers
- Simplify the process for getting financial assistance, especially relative to getting medical equipment for children with special health needs and reducing paperwork requirements.
- Improve the attitude and perception among State employees as it relates to families and children with special health needs. Encourage them to become advocates rather than adversaries.
- Establish a statewide resource network for families and children with special health needs.
- Establish higher income levels for people on Medicaid or prorate the eligibility based on income guidelines rather than simply denying coverage.
- Establish a central resource, possibly an online website, that parents and providers can access for current information about services, programs and funding that is available for children with special health care needs and their families.
- Enhance cultural sensitivity among State employees and pediatric providers, especially relative to Native American cultures.
- Expand funding and/or allocate priority funding to families with a child that has multiple, complex and/or chronic health needs.
- Study the sections of the report which asked respondents to identify one change that they would recommend relative to improving care for CSHN.